

Qualitative study of young people's and parents' beliefs about childhood asthma

Peter Callery, Linda Milnes, Chrissie Verduyn and Jonathan Couriel

SUMMARY

Background: Asthma continues to be a common childhood chronic illness managed principally in primary care. Self-management requires co-ordinated efforts of young people, carers and health professionals. Non-compliance occurs even when parents are supervising care, suggesting that decisions are made on the basis of beliefs that contrast with professional advice. Health professionals therefore need to understand the views of parents (or other carers) and patients to promote good self-management. Little attention has been given to carers' and young people's perspectives on asthma.

Aim: To gain insights into the beliefs of a group of 25 young people aged nine to 16 years old and their carers about asthma and its management.

Design of study: Qualitative study using conversational-style interviews.

Setting: Generally deprived urban areas of Greater Manchester.

Method: Interviews were conducted with 25 young people with asthma and separately with their carers. The interviews were analysed using the principles and procedures of grounded theory.

Results: Carers reported assessing asthma symptoms through observed effects on the child and other family members, including emotions and behaviours that disrupted family life. Young people emphasised the effect of asthma on their everyday lives and in particular the extent to which they appeared different to their peers. Some young people reported continuing symptoms and restrictions of activity that differed widely from the reports of their carers.

Conclusion: Differences between young people's and carers' criteria for assessment suggest explanations for some 'non-compliant' behaviour. Carers' assessment of asthma severity through the absence of acute attacks is consistent with managing asthma as intermittent acute episodes. Professionals should take account of differences between young people's, carers' and professionals' perceptions of asthma.

Keywords: asthma; children; self-care; professional-patient relations; patient compliance; knowledge; patient attitude; practice.

Introduction

SELF-MANAGEMENT education is effective in adult asthma¹ and decreases in young people's use of health services and morbidity are reported.^{2,3} However, evidence of effectiveness of education in childhood asthma is inconsistent.⁴⁻⁶ Medication prescriptions may not be followed, even under parental supervision.⁷ 'Non-compliance' can be considered as behaviour based on beliefs that contrast with those of professionals,⁸ most appropriately addressed in consultations in which patients, carers and professionals communicate their health beliefs.⁹ It is necessary to understand the meanings of asthma and its treatment to young people and carers and how these differ from professionals' understanding.^{10,11} There has been extensive study of adults' perceptions of chronic illness,¹²⁻¹⁵ but the perspectives of young people and their carers have not been systematically addressed.

There have been few qualitative studies of young people's or parents' perspectives of asthma.¹⁶⁻¹⁹ The only study to systematically include both young people ($n = 9$) and parents in interviews used a timeline of events around the last attack as prompts for discussion, suggesting asthma was discussed as an illness of intermittent acute episodes.²⁰ The study reported here is therefore the first designed to include interviews with carers and young people about everyday experiences of asthma. The objective was to assess the health beliefs, perspectives, and concerns of young people with asthma and their carers.

Method

Sample

The sample consisted of 25 young people aged nine to 16 years old with asthma who were prescribed inhaled corticosteroids, and their main carers (usually the mother but including fathers and grandparents).

Participants spoke English as their first language and had no other chronic lung condition. Young people were recruited via a hospital and two primary care practices: the hospital sample ($n = 17$) included young people who made an unscheduled visit to an accident and emergency department or drop-in clinic 12 to 24 months previously. The primary care sample ($n = 8$) was recruited from young people who saw their general practitioner during the same period without subsequent unscheduled hospital attendance. The sample was drawn purposively to include young people diagnosed with asthma for at least one year in an urban and generally deprived community. Most young people were categorised at step 2 of the British Guidelines on Asthma Management (BGAM) indicating moderate asthma,²¹ although all four steps were represented in the sample. Most had not had unscheduled contact with health services during the previous six months (Table 1).

P Callery, RN, PhD, senior lecturer; L Milnes, RSCN, research associate, University of Manchester. C Verduyn, MSc, PhD, C Psychol, director of clinical psychology, Royal Manchester Children's Hospital, Manchester. J Couriel, FRCP, FRCPM, BCHIR, MAMB, consultant in paediatric respiratory medicine, Royal Liverpool Children's Hospital, Liverpool.

Address for correspondence

Dr Peter Callery, School of Nursing, Midwifery and Health Visiting, University of Manchester, Coupland 3 Building, Oxford Road, Manchester M13 9PL. E-mail: peter.callery@man.ac.uk

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HOW THIS FITS IN*What do we know?*

Self-management of childhood asthma requires co-operation between young people, their parents or other carers and health professionals. 'Non-compliance' is reported as a continuing problem. Few attempts have been made to understand childhood asthma from the point of view of parents and only rarely have young people's views been investigated.

What does this paper add?

This study of the perspectives of a group of young people aged nine to 16 years old and their adult carers suggests explanations for some 'non-compliance' and reported differences between young people's and parents' reports of asthma.

**Data collection and analysis**

Interviews took the form of open-ended conversations about experiences of living with asthma. The carer and then the child were each interviewed alone during the course of one visit to the family home. Each interview lasted approximately one hour, was audiotaped and subsequently transcribed. Participants were prompted to discuss the meaning of asthma for themselves and their family and their beliefs about asthma, its prevention and treatment. A topic guide was used to prompt discussion, the topics being selected from a review of the literature (Box 1). The language and themes of participants were followed to avoid imposing the preconceptions of the researchers in the conversation. The topic guide was adjusted as data collection and analysis proceeded concurrently, so that subsequent interviews reflected the emerging concerns of participants, a process of theoretical sampling²² that enabled the study to be responsive and flexible.²³ For example, carers spontaneously expressed uncertainty about how to assess the severity of young people's asthma in early interviews and this topic was included in subsequent interviews.

As well as the procedures designed to maximise sensitivity to participants' language and interests, interviews with

young people were adapted by the use of a role-playing exercise that established rapport and outlined ground rules and expectations for the interview. During the role play the researcher described a recent experience and the young person was invited to ask questions. The exercise demonstrated to the young person that the interview would take the form of a conversation in which the interviewee would talk freely rather than answer a series of questions; that there would be no right or wrong answers; that it was acceptable for the young person to interrupt in this conversation; and that the interview would be recorded. Interviews were conducted by one of the authors — a children's nurse experienced in asthma care but not involved in the clinical management of the young people (PC or LM). Consent was obtained from both the carer and young person, following a visit to the home at which point the study was explained to them. Approval was obtained from the Salford and Trafford Local Research Ethics Committee. Data were collected during the period September 1999 to January 2001.

Interviews were analysed using principles and procedures of grounded theory,²⁴ following transcription and entry into the qualitative analysis programme database NUDIST.²⁵ Data were initially subjected to a process of open coding in which descriptive codes were attached to fragments of data, usually a few lines of text. Data fragments were compared and grouped into conceptual categories. Particular attention was paid to seeking to identify cases that did not fit the conceptual categories, which were adjusted to develop an explanation for the maximum number of cases. An explanation of the relationships between categories was developed that accounted for patterns of similarity and difference in the data. For example, an early descriptive code was 'Acute attacks are what is worrying'. As data collection and analysis proceeded, it was noted that parents' interviews invariably featured this code. Parents were often describing acute attacks that had happened when their children were younger and that had been dramatic and frightening. Young people gave less emphasis to such attacks, reporting them less frequently and most noticeably giving much less emotionally charged accounts. At this point the primary care sample was recruited to test whether this emphasis on acute

Table 1. Children in the sample: distribution of age, sex, BGAM step, and unscheduled contacts with health services during the past six months.

	Male		Female		Total
	Aged 9–11 years	Aged 12–16 years	Aged 9–11 years	Aged 12–16 years	
Number	7	9	5	4	25
BGAM step ²¹					
1	1	—	1	—	2
2	3	4	3	3	13
3	2	4	1	—	7
4	1	1	—	1	3
Unscheduled contacts with health services					
Number of unscheduled contacts	6	8	3	3	20
Accident and emergency attendances	—	—	—	1 ^a	1
Ambulance called	1 ^a	—	—	—	1
GP consultations	—	1	2	—	3
Total	16		9		25

^aAlso consulted GP.

Young people	Parents
Familiarisation and setting ground rules	Description of child's health
Description of symptoms and signs	Description of symptoms and signs
Child's explanation of their own condition	Parents' explanation of child's health problems
Description/explanation of asthma	Description/explanation of asthma
Effects on child's life	Effects on child's life
Impact on family	Impact on family
How does child know that asthma is well controlled and/or that he or she is well/ill?	How does parent know that asthma is well controlled and/or child is well/ill?
What makes child get more ill/less ill?	What makes child get more ill/less ill?
What can child/parents do to prevent illnesses/symptoms?	What can child/parents do to prevent illnesses/symptoms?
How can they help themselves/other people help them?	How can they help child?
Getting help	Getting help
Managing at school	Managing at school
Expectations of future	Expectations of future

Box 1. Summary of topic guides used by interviewers.

attacks would occur when young people had not made an emergency visit to hospital, in keeping with the principle of theoretical sampling.²⁴ References to acute attacks continued to occur in the accounts of parents in the primary care sample, which were explained by parents' use of the presence or absence of acute attacks as a key indicator of whether the child's asthma was controlled. The search for cases that did not fit the emerging pattern was part of the process of saturating the categories; that is, developing an explanation for as much of the data as possible, rather than forcing the data into existing categories.

Results

Trial and error in asthma management

Some carers described assessing and intervening in their child's asthma in a way consistent with a self-management plan. They reported noting early signs of worsening of their child's condition and adjusting bronchodilator and corticosteroid inhaler treatments. More descriptions, however, were of intervention in response to severe symptoms and some included inappropriate interventions, such as the use of corticosteroid inhalers for relief of acute attacks. Trial and error played an important part in decisions about asthma management. Professional advice was tested and adapted to fit with carers' own understanding, developed from experiences of each child's asthma. For example, a mother in the hospital group discontinued her child's use of inhaled corticosteroids during the summer months because she believed that winter weather was the cause of her child's asthma and that suspending corticosteroids would reduce the risk of development of 'immunity' to their effects. A mother from the primary care group described testing whether her 12-year-old child continued to need inhaled corticosteroids:

'I go through this process of just testing it (hmm) emm because he's stronger and his immune system I assume as he gets older is getting stronger, so I suppose I just feel that we have to keep trying because to me he seems better.' [Mother 24.]

Some children also described testing whether they continued to need inhaled corticosteroids:

'I think people have it [asthma] a lot worse than me and it's like I just like don't need it [corticosteroid inhaler] sometimes and I can go, I can go a few days without it. Just doesn't make any difference if I have it or I don't have it.' [Child 12.]

Whereas a few carers gave detailed description of adjusting treatment on the basis of peak expiratory flow measurements, most did not. Some suggested it was unreasonable to require a child to blow into a peak flow meter when breathless. Carers generally preferred their own subjective judgement to peak flow measurement:

'It's a quantitative way of doing it, not a qualitative way of doing it ... it's really hard for you know us the parents to see the wood for the trees ... we just gauge it in a very simplistic way which is that he's not having prolonged bouts of it, he's having, err, short shallow bouts of it, that's tolerable for him.' [Father 23.]

Objectives of management and 'tolerable' asthma

This father's reference to 'tolerable' asthma summarised the views of other carers. Carers sought to minimise the physical, psychological and social impact of asthma and treatments. Their objectives for asthma management meant that some accepted a level of symptoms and restriction of activity as 'tolerable'. For example, some families kept furry pets, despite knowing that health professionals would advise that this could worsen their child's symptoms. Because trial and error was used to decide whether to follow, adapt or reject advice from health professionals, carers' beliefs about what constituted 'tolerable' asthma have particular significance. The trials reported by carers illustrated how they sought to reconcile competing concerns, such as minimising asthma symptoms through the use of preventive inhalers and minimising their child's exposure to steroids. They used trials without corticosteroids to decide how to balance beliefs about possible side effects with beliefs about the effectiveness of these drugs in preventing asthma. There were other competing concerns; for example, watching over a child and allowing independence:

'It's on your mind all the time, emm, day to day it's has

he took his inhalers (yes) and kind of wanting to keep an eye on him without smothering him (yes), it's a balance.' [Mother 5.]

There were complex interactions between choices. Parents described their reluctance to make their children different from their peers by restricting activities, but some described this as necessary to avoid the risks of asthma:

'You just have to explain it that she can't, you can't run without getting out of breath and there's no point in pushing it, is there? She'll only end up ill.' [Mother 18.]

The notion of 'tolerable' asthma was therefore important in reconciling competing concerns involved in decisions about prevention and treatment of asthma. 'Tolerable' referred to the overall effect of asthma on the child and family and could include acceptance of restriction of activities as a method of limiting symptoms. Assessment of asthma was uncertain:

'Are we at the lowest end and we're just coasting along and err, or are we middle? You could only see your child as he or she is. (Hmm) I don't have another asthmatic to compare it to.' [Mother 8.]

Young people's reports and carers' own observations of the visible effects of asthma were therefore assessed against the standard of whether asthma was 'tolerable'.

Carers' assessments: acute attacks and other visible effects

Acute asthma attacks were an important element in carers' assessments of their children's asthma. Carers' accounts typically followed a structure in which a story of frightening asthma attacks in the past contrasted with a picture of the child as currently healthy. Carers repeatedly stressed concerns about acute attacks and described graphically their children's attacks and their own feelings of fear and anxiety. Fear of acute attacks also featured in interviews in the primary care sample:

'Would he have an attack I don't know. I always assume that he wouldn't but there's always that small percentage that he might.' [Mother 24.]

In carers' accounts, asthma was generally characterised as an illness of acute attacks with severe symptoms of breathlessness, cough and wheeze. Managing asthma involved a process of trial and error in which different medication regimens and non-pharmacological interventions were tested. Whether the child was experiencing acute attacks was an important component of tolerable asthma:

Interviewer: *'So how's her asthma then?'*

'Well like I say she doesn't have anything where she'll end up in hospital (hmm). She might have a few odd twinges, pains in her chest but other than that she'll be fine. As soon as she takes the inhaler she's all right then.' [Mother 22.]

Interestingly, this reference to 'odd twinges' contrasted with the daughter's own account of being distressed by chest pain. In addition to acute attacks, carers referred to observed effects of asthma. Worsening asthma was also recognised through changes in mood and behaviour:

'Oh he's wheezy, coughin', very arrig..., very bad mood he is, you can't really talk to him, (right) really stropky he is and then he'll start on his brothers and sisters for no reason.' [Mother 3.]

Even physical symptoms were sometimes described in terms of their effects on other members of the family; for example, coughs were described as 'annoying', 'constant' and 'keep us up all night'.

Young people's perceptions of asthma: 'good' and 'bad' days

Young people described their asthma differently. When they talked about acute attacks, they spoke with less intensity than carers. They discussed the 'here and now' rather than their experiences of acute attacks in the past. Young people emphasised the effects of asthma on their everyday lives, illustrated by discussion of 'good' and 'bad' days. Good days were when they felt 'normal', 'like other people', 'can run as fast as other people', 'do netball without stopping', asthma 'doesn't worry me'. The emphasis was therefore on whether the child appeared different from peers:

'Well, a good day would be, would be, kind of emm, emm, err, I didn't have any asthma and I wouldn't be coughing (hmm) yeah. I try not to cough in assemblies because then I get embarrassed ... we had these class assemblies and I was coughing and coughing in one of the assemblies and everybody was looking around.' [Child 23.]

Whether a day was 'good' or 'bad' was largely determined by how visible asthma was to other children and could therefore be influenced by the child's schedule; for example, whether sports featured on the timetable, as well as by changes in airway obstruction. Some children accepted limitation of activities as inevitable; for example, this child whose asthma was categorised as moderate:²¹

'I think it's normal because I don't know anything different ... I can't remember not running for a long time and not be wheezy.' [Child 5.]

When this quotation is set next to a comment of the same child's mother, it is apparent that there were some notable differences in the picture of asthma presented by young people and carers:

'I have to really remind him to take his Ventolin because he's so unused (yes) to having wheezy attacks.' [Mother 5.]

When we compared interviews of individual young people with the interview with their carer, nearly half of the young people described limitation of activity and experience of reg-

ular symptoms that varied considerably from the picture of generally good asthma control presented by their carers.

Discussion

Summary of main findings

Carers and young people used trial and error to decide how to minimise the physical, psychological and social impact of asthma and treatments. Asthma could therefore be characterised as 'tolerable', even in the presence of continuing symptoms. Carers reported assessing symptoms through observed effects on the child and other family members, including emotions and behaviours that disrupted family life. Young people emphasised the effects of asthma on their everyday lives, illustrated by their accounts of 'good' and 'bad' days, which emphasised whether asthma made them appear different to their peers. Some young people's accounts indicated acceptance of continuing restrictions of activity and their accounts could differ markedly from those of carers.

Strengths and limitations of this study

Strengths of the study include: recruitment of young people who had few recent unscheduled contacts with health carers from hospital and primary care sources; the systematic inclusion of young people's and carers' perspectives; and interviews that enabled examination of participants' own perspectives of asthma.

Limitations include the representation of diversity in the sample: young people lived in generally deprived urban areas, with limited ethnic diversity and spoke English as their first language. Further study is required of the perspectives of young people and their carers from a wider range of cultural backgrounds.

Study findings and the existing literature

The use of trial and error to adapt the advice of health professionals is consistent with adults' reinterpretation of action plans from the perspective of their own experiences with asthma.²⁶ Most carers preferred to rely on their own subjective judgements of their children's asthma rather than peak flow measurement, which could be why peak flow measurement is unreliable.²⁷ Beliefs that young people were growing stronger and could therefore manage without corticosteroids, or that suspension during the summer would reduce the risk of 'immunity' developing, explained some carers' decisions not to follow advice to continue with corticosteroid prophylaxis.

Carers' objectives of minimising the effects of asthma and the concept of 'tolerable' asthma are consistent with accepting symptoms and restriction of activity. Carers' concerns about acute asthma attacks and associated feelings of anxiety and fear formed the context within which they assessed their children. Education associated with acute episodes can be effective,² perhaps because acute attacks present a window of opportunity of motivation to improve self-care.²⁸ However, it could reinforce carers' beliefs that asthma is an illness of acute episodes and underplay the effects of everyday symptoms that do not lead to acute attacks, but nonetheless affect young people's quality of life. The priori-

ty given to avoiding acute attacks is consistent with treating asthma 'as an intermittent acute disorder'.²⁹

Although tolerance of symptoms has been described before,²⁰ a distinction has not been drawn between parents' and young people's perspectives. Young people emphasised acute attacks less than the everyday effects of asthma symptoms on their lives. Some young people's accounts of their asthma varied markedly from their carers and suggested that they were experiencing continuing symptoms and accepting restriction of activity as inevitable, although their treatment regimen would classify them as having moderate asthma. Differences between young people's and parents' perceptions of asthma have been reported. In epidemiological studies, young adolescents report significantly more asthma symptoms than do their parents.³⁰⁻³² Parents' assessments correlate moderately with measures of airway calibre and control but not with quality of life in children under 11 years old. Over the age of 11 years, young people's assessments correlate more highly with all measures than do their parents'.³³ It is therefore inappropriate to substitute 'parent' for 'patient' in self-management education. The different criteria used by young people and carers that we have reported suggest an explanation for differences in young people's and parents' accounts of symptoms.^{30,31,33} Carers' judgements of tolerable asthma risked overemphasising their concerns about the observable effects on the child and family and underemphasising everyday experiences of asthma. The concept of 'good' and 'bad' days could provide a basis for developing child-centred approaches to self-management education that reflect young people's concerns and objectives, as well as those of professionals and other adult carers.

Implications for future research and clinical practice

Interventions and research in childhood asthma should take account of the different perspectives of, and the need for effective communication between young people, carers and professionals. It appears that participants responded to the aspects of asthma that impinged on themselves in interviews: carers discussed their fear of acute attacks and the effects of asthma on the whole family, while young people emphasised their everyday experience of living with asthma. The differences between the perspectives of young people and their carers indicate the importance of involving young people in their own health care. Self-management education could be more successful if young people are involved in the construction of self-management plans that reflect their own experiences, concerns and objectives. The available evidence about consultations is that young people have few opportunities to express their own views.³⁴ Health professionals should seek the views of young people about their care and should encourage carers to involve young people in self-management of chronic illness. There is increasing recognition that children identify and act to achieve their own objectives^{35,36} and so can take some responsibility for their own health care. Health professionals should recognise and support the roles that young people can play in self-management of chronic illness.

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